

## The Aggregate Community Picture

By EDNA NICHOLSON, M.S.P.H.

**A**TTITUDES are the source of action whether they are those of the individual or of a community of individuals. Community attitudes toward cancer are vastly important because of the ways in which they affect human suffering and what is done to relieve it.

Community-wide participation is essential if the necessary services and facilities are to be available. Effective provision of these services and facilities involves significant numbers of highly trained personnel, necessitates the spending of large sums of money, and requires good community planning and coordination.

Unless effective community provisions have been made, little can be accomplished either on a mass basis or in obtaining good diagnostic and treatment services for an individual patient. Provisions must include:

*Research.* Research does not consist of some form of magic. It does consist of endless hours of painstaking effort by highly trained personnel, working with specialized and often very expensive equipment in places where the necessary material is available, the facilities are adequate for their needs, and the funds are sufficient to meet the cost.

*Education of professional personnel.* Well-staffed, well-organized, and well-financed educational and training centers are essential if there are to be good doctors, nurses, social workers, health educators, laboratory and X-

ray technicians, and other essential personnel available when needed.

*Education of the public.* Not enough is known about cancer to cure all cases even though discovered early. But the number of persons dying for this reason is perhaps far less than the number who are suffering and dying because they did not seek care early, or did not present themselves to reliable physicians, or did not follow the advice they received at a point where it might have controlled the condition and saved their lives. Procrastination and quackery are making ready victims of cancer patients. Broad and effective community programs are needed to educate the public.

*Hospitals and related facilities and equipment.* Facilities are needed for diagnosis, for surgical care and other types of treatment, and for good care of patients, including terminal care. The size, complexity, and cost of these facilities and equipment are such that there is little or no possibility of providing them without broad community participation.

*Coordination of services.* To achieve the best possible care for patients and the most efficient use of community money, there must be provisions for coordinating the many specialized services which may be required for the individual patient and adequate machinery to achieve effective coordination in community planning and action. This need was sharply delineated in a recent study of terminal care for cancer patients. Intensive study of more than 5,000 cases in an urban area showed that, in general, almost enough facilities and services were available in the community to provide the necessary care, but that many patients were not receiving the care they needed because they did not know it was available, or because the patients needing

---

*Miss Nicholson, director of the Central Service for the Chronically Ill of the Institute of Medicine, Chicago, presented this paper as a part of the American Cancer Society's program at the National Conference of Social Work held in Chicago, May 27, 1952.*

---

the care and the resources available to provide it were not getting together. Deficiencies in community resources need to be clarified, unnecessary gaps and duplications eliminated, development of new facilities and services guided, and existing sources operated and used with effectiveness for the patients and economy in expenditure of community money.

*Meeting the costs of medical care.* Provisions must be adequate for persons unable to pay. At present we have far too many different public assistance programs responsible for financial help to needy people, with too much personnel and money being wasted in maintaining artificial distinctions between specialized, categorical programs. And almost all of them are operating on seriously inadequate standards in staff and services and in the assistance they are providing to needy cancer patients along with other dependent people.

Obviously, there are many factors which influence the adequacy with which any community provides the services necessary in the control of cancer and in the diagnosis, treatment, and care of persons suffering from cancer. Highly important among these factors are the attitudes with which the community regards cancer and its responsibility for meeting the problems related to it. There is nothing mysterious about community attitudes. They represent merely the aggregate of the attitudes of the individuals who make up the community. If most of the people in the community regard cancer with such fear or guilt that they cannot accept the problems calmly and plan wisely to meet them, these attitudes almost certainly will be reflected in poor community planning, disorganization, and inadequate services. If a majority of the individuals in the community are selfish and indifferent to the problems of people who are sick and in trouble, their attitudes will be evident in lack of effective community support and an inability to develop and maintain good services. Conversely, when a majority of the individuals in the community feel a sense of responsibility for their fellow men; when they are realistic and objective in facing facts; when they are moved by humane understanding and intelligent compassion, their community will have good services and the fullest advantage will be taken of all existing possibilities for the prevention

and control of cancer and for the diagnosis, treatment, and care of persons affected by it.

### **Fear of Cancer**

One of the most prevalent and potentially damaging attitudes toward cancer is fear. The fear of an individual that cancer may strike him or that it may take away someone he loves is so widespread as to be almost universal. It may be a normal and perfectly intelligent reaction to reality. It is one of the strong factors which helps to motivate intelligent people to consult a physician and to follow his advice. It causes communities to provide the money and to take the action necessary to assure that good services and facilities are available for the management of cancer.

However, uncontrolled fear of cancer is likely to defeat the very purposes it should serve. Uncontrolled fear may be evidenced by refusal to face the facts and by consistent efforts to avoid all contacts with realities which must be faced if anything constructive is to be done about cancer. This results almost inevitably in a lack of sufficient services, inadequate support for good services, and poor planning—or no planning at all—in the development of new facilities and services.

Often fear of cancer results in such panic that there are intense demands for community action, but the demands are accompanied by such strong emotions as to make sound, realistic planning impossible. New facilities then may be developed blindly only to discover too late that they are not of the type suitable to meet the real need. Uncontrolled fear may be expressed in the form of a paralyzing hopelessness which makes it difficult or impossible to develop and maintain good community services.

### **Association of Guilt**

Feelings of personal guilt are widely prevalent in the care of cancer patients. Usually, they arise from situations in which relatives become deeply disturbed by some failure, or imagined failure, in their past relationships with the patient. As they face the more or less imminent possibility of the patient's death they may be almost overwhelmed by their feelings

and may begin to reach out frantically for ways in which they can compensate for their failures and reassure themselves regarding their devotion to the patient and their general worth as human beings. These feelings probably are much more widespread than is generally recognized. Like fear, guilt may be so common as to be part of a normal reaction.

Some release for the feelings is essential. In many instances, of course, the individual is able to adjust to the situation with reasonable success. In others, however, he may be so driven by his feelings that he becomes excessively protective of the patient, oversentimental about all cancer patients, critical of the doctors, nurses, hospitals, and others in the community, and a source of disturbance in efforts to meet community problems. He may find others who share his emotional distress and his feelings of rebellion. Another "crusading" group in the community may be the result, guided by emotion rather than facts and acting on impulse without sound guidance—and sometimes in rebellion against sound guidance. Groups of this kind tend to spring up everywhere. Usually, they do not reach sufficient size nor have sufficient stability to achieve substantial results of any kind. They may endanger good community services, however, by diverting badly needed interest and support from those which have value to those which do not.

#### **Bane of Self-Interest**

It is an entirely normal reaction for each individual to consider, first, his own comfort and security. It is not surprising, therefore, that self-interest is found in community services for the management of cancer just as it occurs elsewhere in human life. There are varying degrees, however, in the attitudes of individuals and communities toward their fellow men. In some the prevailing attitude seems to be one of indifference—or even of censure—for people in trouble. Where little, if any, feeling of community responsibility for people who are hopelessly sick and dependent exists, it is difficult or impossible to develop and maintain good community services.

In other places, the situation seems to be only slightly better. These communities may not

be able to ignore their responsibilities completely. They may enact laws making legal provisions for the care of sick or helpless people, but, because they are not willing to make real sacrifices of their own comfort and security, they may give so little financial and other support to the programs that the laws have little effect.

In some communities, various civic and professional groups may deplore the absence of good community services but be unwilling to submerge their own vested interests sufficiently to achieve effective, well-rounded community action. Social workers criticize physicians for not supporting a plan which the social agencies develop. Hospitals and doctors criticize the social agencies. Businessmen and labor leaders are critical of all of them. And while each is blaming someone else because the community does not have the facilities it needs, no one is submerging his own particular interests and point of view long enough to make an honest effort to understand the problems of the others; and the people who desperately need care continue to be left without it.

There is another aspect of self-interest which also may endanger good community services for cancer patients. Often it is a subconscious type of self-interest buried under an apparently sincere and zealous devotion to the development of good health and welfare services in the community. There are persons and organizations who sponsor a "cause" in an effort to gain social prestige. There are others who are hungry for personal glory and power and are willing to work hard for good community services only so long as they can dominate them and receive widespread credit and publicity for their good deeds. These people and groups in the community often are motivated by self-interest of this kind without fully recognizing it. They may believe themselves to be concerned sincerely for the welfare of the people they supposedly are serving.

#### **Constructive Attitudes Toward Cancer**

Fortunately, in every community there are attitudes which have constructive effects upon the development and maintenance of good community services. In all communities these

attitudes are present to some extent. Even in those places where they seem to be overshadowed by less wholesome attitudes, it is probable that they can be found in some degree and, with care, can be increased to a point where eventually they predominate in controlling community action.

In any effective effort to assure good facilities and services to meet the problems presented by cancer, it is important that such attitudes characterize the planning and action of the community.

A sincere sense of responsibility for helping people who are sick and in trouble implies more than a sentimental desire to relieve suffering. It includes a broad responsibility for assuring that real, practical help of good quality and adequate amount actually is provided and kept consistently available.

A realistic acceptance of the importance of factual information with careful analysis of problems, sound planning, and consistent long-range effort is essential. The problems which now stand in the way of good community facilities and services for cancer patients have been growing for many years. They are deeply rooted and are intertwined with many other health and welfare problems in the community. If they are to be solved, there must be accurate information about what the problems really are; how much is being done to meet them; what specific factors are operating to cause the existing deficiencies; how these factors can be overcome; specifically what new facilities and services are needed and how many; where they should be located; how they should be operated; what their relationship should be to other essential community services; and how these facilities and services can be financed. These patients have waited too long, and their needs are too desperate, for us to fail them now by not accepting the need for clear thinking and long, hard work.

There are many individuals and many communities who would like to have better facilities and services available for cancer patients. Too often, however, their desire for these services is spasmodic and does not go deep enough to accept and meet the necessity for assembling and analyzing factual information to clarify the needs, for formulating effective plans for

meeting them, and for working consistently over long periods of time to assure that the needs are met. Instead, they tend to seize upon whatever idea presents itself on the spur of the moment and to base their actions upon superficial thinking and too few facts.

It is under circumstances such as these that communities fail to distinguish clearly between a need for more beds for cancer patients and a need for more adequate funds to pay for care of patients in beds which are available. This type of approach may lead to the development of specialized hospitals and related institutional facilities exclusively for the care of cancer patients, when closer integration of cancer facilities with general hospitals and medical centers might provide better services and entail less cost to the community. The same approach may be responsible for the "pesthouse" type of planning which establishes separate institutions exclusively for terminal care of cancer patients. All of these things may be done with the best possible intentions. Certainly, good intentions are greatly needed. They must be supplemented, however, with a realistic understanding of the need for facts and clear thinking.

Understanding and acceptance of the emotional aspects of human behavior and the emotional requirements of the individual is another community goal. We have tried too often to choose between intelligence and emotion on the assumption that these two qualities necessarily are antagonistic. Yet, the human being is an indivisible combination of both qualities, and there is no way in which human needs can be met adequately without consideration for both.

For humane reasons, the emotional effects of various types of facilities and services must be fully considered. Because of the strong influence of emotions on human behavior and on the ways in which community services are used by people in need of care, it is essential also for very practical reasons. It is unrealistic to attempt to plan community services without consideration of the probable emotional reactions of the patients, their families, and the community to the various types of services under consideration. Similarly, intelligence must be used if there is to be any hope that the services will be stable, well-operated, and effective.